

Heaviness, intensity, and intimacy:**Dutch elder care in the context of retrenchment of the welfare state**

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Abstract

In the Netherlands the recent shift to a ‘participation society’ has led to a reconfiguration of health care arrangements for long-term care. The new long-term care act, scheduled to commence January 2015, forms the political realization of the participation society: people are expected to decrease their dependency on state provisions and instead become self-sufficient or dependent on family and community solidarity. In this Think Piece we argue that the implicit references of policy makers to pre-welfare state community solidarity and self-sufficiency do not adequately consider the historical and social embeddedness of care. Referring to Rose’s concept of ‘politics of conduct’ we argue that in framing care as a moral obligation, the current politics of conduct may obscure the physical and psychological heaviness of intimate care between family members, the diversity of care relations, and their sociohistorical embeddedness.

The participation project

In recent years health care arrangements in the Netherlands have changed rapidly. The combination of rising care costs, an aging population, and the 2008 global economic crisis has led to a series of austerity measures aimed at cost containment and reduction in recent years. These austerity measures go hand in hand with a more ideological project: the gradual shift from a caring state to a ‘participation society’¹ based on the claim that the welfare state contributed to a loss of social solidarity and individual responsibility.

¹ The notion of the participation society (*participatiesamenleving*) was first mentioned in the King’s Address to the Nation (Troonrede) of September 2013. In the document ‘Doe-democratie’ the cabinet outlines their ideas about involving citizens (Kamerstukken II 2012–2013, 33400 VII, 79). In follow-up discussions the Dutch government has explicitly stated that although the move towards the participation society is the new policy agenda, vulnerable citizens will still be able to use the facilities of the caring state (Letter of the Prime Minister April 2014); see http://pe-webservice.persgroep.nl/static/asset/2014/participatiesamenleving_4741.pdf.

The reconfiguration of health care arrangements for long-term care in the Netherlands (see Hiddinga 2014) forms the political realization of the participation society. Care reform started in 2007, with the decentralisation of care to municipalities. A new policy, scheduled to commence in January 2015, aims to further shift care from professionals to informal caregivers (relatives, neighbours, friends, volunteers). This is established by imposing stricter eligibility criteria for professional care.

The underlying idea of the participation society is one in which people decrease their dependency on state provision and instead become self-sufficient or dependent on family and community solidarity (Etzioni 1993, 1997). Rose (2000) has termed this new approach to citizenship as a ‘politics of conduct’; rather than framing citizens as rational beings or as social beings, a politics of conduct centralises values as individual morality, organisational responsibility, and ethical community. A politics of conduct creates new links between the personal and the political. Citizens are still autonomous beings but are citizens of neighbourhoods, associations, networks, and age groups – rather than national collectives (Rose 2000, 1398).

For elderly people in the Netherlands everyday care arrangements will change radically. In public discourse doomsday scenarios point to the loss of care for large groups of elderly people, and worry about increasing social isolation. In both public discourse and policy, ‘care’ is used like a container, holding a range of meanings but hardly analysed, let alone placed in historical perspective. Using our own expertise – as a sociologist looking at welfare state transformations from a comparative perspective (Da Roit), and as an anthropologist looking at family care for older people (de Klerk) – we explore what ‘care’ means in the everyday lives of elderly people in the Netherlands today and what the participation society project might ‘do’ to care and care relations. We present care as a ‘moving object’: its meaning changes over time and is shaped according to specific contexts of care.

The welfare state era: Freed from care

For at least the last forty years, health care arrangements for long-term care in the Netherlands have been characterised as ‘services-led’ (Da Roit 2012), meaning that care responsibilities for older and chronically ill or disabled people are outsourced to professionals rather than being a family responsibility (Leitner 2003, 358). This was made possible through the introduction and the

expansion of a national insurance programme, the Exceptional Medical Costs Act (Algemene Wet Bijzondere Ziektenkosten, AWBZ) in 1969. In its early years, the AWBZ usually financed stays in nursing homes and retirement homes. In the 1980s and 1990s care in institutional settings was gradually reduced in favour of in-home care services. The shift from institutional to home care was based on the assumption that (older) people with disabilities would prefer to live independently and that home care would cost less than institutional care. Care was categorized into several domains, each requiring its own special skills: physical care, household care, daily assistance, and medical care. Care, in other words, became measurable, specific and assigned to specific groups of professionalised people.

The increasing formalization and categorization of care under the welfare state also removed certain aspects of care from intimate social relations; the welfare state took over the heavy, smelly, and scary aspects of care from families. This permitted family members, friends, and neighbours to support each other emotionally, to do small things for each other, and to step in when needed, but only when they wanted to. Comparative research has shown that informal care giving is actually more widespread in strong welfare states like the Netherlands, but it is less intensive and less oriented to personal care (Haberkern and Szydlik 2010; Motel-Klingebiel et al. 2005; Brandt et al. 2009).

Health-care arrangements in the Netherlands for the past thirty years have been informed by an idea that all citizens are autonomous persons with an equal right to care. As citizens, all people in need of support were entitled to care; those requiring care should not need to depend on themselves or family members to obtain that care; and informal caregivers should have the choice to (not) care. In short, public care was a means to create autonomy and freedom from caring, both for people in need of care and for their family members.

Restructuring the welfare state: Towards a morality of interdependency

In the late 1980s and 1990s the costs for long-term health-care arrangements in the Netherlands were on the rise. Population aging, and the increasing medical possibilities to keep people alive, has led to a generation of elderly who are increasingly living with chronic or long-term illness. Moreover, the gradual reduction of institutional care has contributed to the increase of care needs among people living independently (Da Roit 2010).

To reduce the costs of care, attempts were made to reform the AWBZ in the 1990s when market principles were introduced into the care sector. Care came to be framed as a commodity that could be bought by consumers (Mol 2008). For example, the allocation of ‘personal budgets’ to individuals, as an alternative to regular services, was introduced, but this had no direct effect on the containment of costs (Da Roit 2012). The idea that the AWBZ itself should be reduced in scope began to gain ground (SER 2000). An important turning point was the introduction of the Social Support Act (Wet Maatschappelijk Ondersteuning) in 2007 when municipalities took over some of the ‘tasks’ previously covered by the AWBZ. Decentralisation was seen as a radical and effective means to reduce costs; to become eligible for municipal support, people in need of care first must exhaust their own resources. Current reforms promise to continue in the same direction. The new Long-term Care Act (Wet Langdurig Zorg, WLZ), to be implemented in January 2015, will replace the AWBZ, but will only support those people in need of twenty-four-hour care, either in institutions or at home. Although entitlement criteria for the WLZ are still under discussion, it is certain that it will be more difficult to qualify for care and that access to institutional care will diminish. Those who do not meet the new criteria will be asked to rely on health care funded through health insurance and to mobilize their informal network before applying for municipal care.

A significant body of research has examined how reconfigurations of the welfare state have shaped public discourse on citizenship over the past fifty years in the Netherlands (Tonkens 2008; Hurenkamp et al. 2011; Keat et al. 1994; Newman and Tonkens 2011; Cox 1998). Austerity measures in recent years have rapidly changed policy discourse about equal rights and care for all, introducing a do-it-yourself paradigm where self-reliance and self-sufficiency are termed as moral elements of good citizenship (Grootegoed 2013). Current health-care reforms are challenging feelings of autonomy and affecting how people relate to their informal care networks, for example, by seeking increasingly less care to protect their feelings of autonomy (Grootegoed et al. 2010; Grootegoed and van Dijk 2012; Boyle 2008; Peeters and Cloin 2012).

The current restructuring of long-term care in the Netherlands will bring with it a historically unprecedented situation: the emergence of heavy, intensive, twenty-four-hour home care of people who previously qualified for institutional care. Under the new system, many people currently living

in nursing homes will be encouraged to start living independently or with family.² Although proponents of such changes may argue that families routinely provided care prior to the advent of the welfare state, we argue that the shift is historically unprecedented because the care needs of elderly in contemporary society have vastly changed over the last half century, as have family living arrangements. Against this background we see two trends in current policy discourse: the tendency to refer to an idealised past with notions of ‘lost values’, and the tendency to see care as disembodied from concrete social interactions and relations.

Participation 1.0: Care before the welfare state

In current policy discourse about welfare state reform there is a tendency to simultaneously lament the loss of social solidarity and the loss of individual responsibility. Such discourses are marked by a degree of nostalgia, referring to the era before the welfare state as a time when such social and individual qualities thrived. Such a position, however, seems to oversimplify historical and social realities.

Even if public long-term care policies in the Netherlands and in other Northern European countries were a relatively recent invention, care institutions have a much longer history. In the Netherlands institutional care for elderly people included ‘poor houses’, where destitute elderly received care. One of the conditions for receiving care was submission to strict social control over everyday activities. Psychiatric institutions served to control poor, old, disabled, and mad people. Gradually these institutions evolved into older peoples’ homes and other specialized care institutions (De Swaan 1989). In the 1940s and 1950s, some rural communities had social welfare schemes for the destitute (van den Boom 2003). Do these forms of collective support represent the ‘community solidarity’ mentioned in current policy discourse? And if not, where exactly do we situate the age of self-reliance, or the era of family solidarity? Before the emergence of these forms of collective support?

We also know very little about the phenomenon of informal care prior to the welfare state and how it has transformed itself in the transition to the welfare state, but the limited historical research on the social practice of family caregiving argues for attention to the diversity of caregiving across

² Moving out of institutional care does not necessarily mean a loss of all formal care assistance. Older people currently receiving care through the AWBZ will be reassessed in terms of the assistance they require.

different socio-historical contexts (Hareven 1996). Informal family care has likely long been a central part of elder care in the Netherlands. But we do not know much about when, how, and how long family members have been caring for each other. We also do not know how informal family carers and older people themselves defined care and what they expected from care. Our hunch is that moral obligations to provide care have always been present and there have always been informal ways to secure informal care in the absence of family caregivers.³ At the same time we think the increasing professionalization and medicalization under the welfare state has inevitably changed not only the content, shape, and meaning of care, but also the experience of aging. The common situation aging with chronic ailments has most likely affected the physical experience of aging in the Netherlands.

Practices of care and their meaning cannot be abstracted from the socio-historical context in which they are embedded. In the Netherlands the gradual institutionalisation of care has changed not only the division of care responsibilities between institutions and families but also the conceptualization and experience of informal care (Abel 2000). We wonder whether the politics of conduct articulates standards for family care that were actually never there before? The nature and social significance of family and community care is likely to have changed together with wider social transformations.

Participation 2.0: Embodying and embedding care

In the current public discourse, ‘care’ can be anything and may happen between anybody. Care is helping out your neighbour with calling up the telephone company, accompanying your mother who has dementia to the doctor or changing her diaper, and helping your mentally disabled/challenged child with his homework. But can we really abstract care to this extent and disembed it from the specific social relations in which it takes place?

Smelly care

We see a return of smelly care in intimate relations between lay caregivers and care receivers. Care is not just loving, warm, and affectionate. Care is also characterized by disgust and contention, cleaning

³ In one of the rural field sites studied by de Klerk, elderly people claim that in the 1940s and 1950s they wrote wills in which they arranged the inheritance of property (houses and land) in exchange for care and rights to remain living at home until death. These written agreements could be made with one of the children or in case of elderly without children with an unrelated person (2014, informal interviews).

soiled trousers, masking the smells of urine: it is – especially in Dutch society where autonomy is conjoined with the privacy of the body – about an intimacy that weighs heavy on both caregiver and care receiver. Care is unruly and messy (Mol 2008). An elderly person might not need care twenty-four hours a day but might need specific care at a specific and unexpected moment; assistance to go to the toilet or to wash, someone to pick you up when you fall down or to settle you when you are confused. This care is intensive and requires the presence of informal caregivers.⁴ Informal caregiving can, depending on the condition of the elderly person needing care, take not only a heavy emotional but also a physical toll on informal caregivers (de Klerk 2014). Practices of care are not just social but are also bodily encounters, and the constantly changing, aging body affects social interaction, especially in physically demanding care encounters (Shilling 2008; Nettleton and Watson 1998; Livingston 2005; Mol 2008). How will these confrontations with smelly care subtly redefine our notions of care and the place of the body in intimate relations?

Recent scholarship shows that older people themselves are often informal care providers (CBS 2013; de Boer and de Klerk 2013; Van Nimwegen and van Praag 2012; Schenk et al. 2013), and that they actively seek to organise care by using telecare and alternative living arrangements (Van den Boom 2003). While all this is possible when older people in families have mild care needs, it becomes a problem when those needs intensify. How is autonomy in informal care relations linked to the concept of the independent body? What will happen when bodies become dependent, when relatives increasingly have to provide physical care?

At the moment informal family care in the Netherlands is marked by the division of tasks among many people. We envision a trend towards a heavier burden for fewer informal family caregivers. Moving smelly care into the family will depoliticize it, and it may lead to greater social isolation of both caregivers and elderly and to the search for alternative solutions to safeguard physical autonomy. Recent data – which should be taken cautiously and would need further investigation – indeed suggest that in the second half of the 2000s the number of professional caregivers has decreased, even while the intensity of caregiving has increased (Oudijk et al. 2010; Cloin et al. 2013).

⁴ In the Netherlands informal caregivers are called ‘*mantelzorgers*’. Often they are female, and middle-aged and older (over fifty years of age) relatives like partners and daughters, but sometimes they may be unrelated volunteers.

When cutbacks result in less institutional support, the expectation is that not only relatives but also volunteers take over informal care. Expecting the greater involvement of a community of ‘voluntary unrelated people’ (one of the core ideas of the new participation thinking), moves beyond the fact that in current Dutch society ‘heavy care’ has been outsourced to professionals for years and that only a few intimate others are involved in this type of care. Expecting volunteers to take over smelly care does not take into account the particular relationship of intimacy required in this kind of care.

Thinking about the intimacy of care leads to thinking about the kind of community and the kind of care we are talking about. The Netherlands has a history of rich social networks that are central in providing all sorts of support – and this is often not acknowledged in the public debate. But this does not automatically mean these networks can be applied in all sorts of care. Relying uncritically on informal caregivers or unrelated volunteers to step in means we are risking an extreme form of social isolation among those needing intimate care and among their primary caregivers, who already feel overburdened (de Klerk and de Boer 2014). While informal caregivers would like more recognition, such recognition also formalises their role and replaces voluntary care with a moral obligation to serve as the principal actors in the new participation society. The return of smelly care in intimate relations might lead to more interdependency and less autonomy of both caregivers and care receivers rather than more individual self-responsibility.

Unequal care

A growing diversity and inequality in the forms of care could emerge in the new participation society. The current policy debate around the reform of Dutch health-care arrangements for long-term care does not touch upon the possible development of an alternative to the welfare state and family/community care: market care. Privately paid care is well known in historical accounts of rich (urban) families, where family members lived together with servants. Moreover, the considerable development of care markets based on migrant care workers in, as a substitute for, or a complement to family care is a reality in several Northern and Southern European countries (Da Roit 2010; Da Roit and Le Bihan 2011; Da Roit and Weicht 2013).

The return of smelly care in intergenerational relations might lead to an increasing polarisation in the arrangements of informal care between people who can afford to outsource care and people who cannot – thus creating unequal care. The current logic of long-term care in the Netherlands, based

on rights for all and inclusive care, might in practice, disappear in the participation society. In the future, migrant care workers – now a very small group in the Netherlands (Da Roit and van Bochove 2014) – might become much more numerous. For those who can afford to outsource care, an increasing privatisation of nursing homes might also become an option. For yet others, a return to family care as it was configured before the welfare state might become a reality, but with many more contentions over how informal caregiving should be shaped in the face of increasing social and spatial mobility and contemporary expectations about autonomous life.

Conclusions

In this Think Piece we have presented care as a moving object: what we now call ‘care’ is different than what care was in the pre-welfare state and welfare state eras. The Dutch ‘politics of conduct’, seen in the ideological projects of participation and self-reliance, do not adequately consider the historical and social embeddedness of care. In framing long-term care as a moral obligation (with implications for families that choose to outsource care), this politics may obscure the physical and psychological heaviness of intimate care. The intensity of this intimacy, and the consequent tensions that may arise between informal caregivers and elderly in need of care, deserve our attention.

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and Social Care in the Community, Social Policy and Administration, Social Politics, Journal of European Social Policy, European Societies, Family Issues).

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